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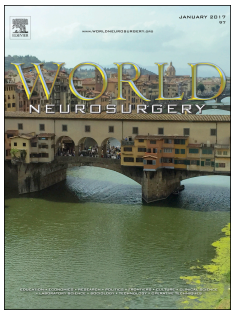

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Title:

Patients' expectations and satisfaction in subthalamic nucleus deep brain stimulation for Parkinson disease: 6-year follow-up

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Deep brain stimulation, expectations, Parkinson disease, satisfaction, subthalamic nucleus

Running title:
Expectations in STN DBS

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The authors' institution has received educational grants from Medtronic, Abbott, and Boston Scientific.

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Abstract:

Objective:

Patients' expectations are considered to play an important role in STN DBS. We explored the relationship between expectations, satisfaction and outcome 6 years after surgery.

Methods:

15 patients with Parkinson disease (9 males, mean age 60.5 ± 6.4 years) undergoing STN DBS completed a modified PDQ-39 questionnaire (incorporating an assessment of patients' expected changes in addition to the standard quality of life items) preoperatively and at 6 years postoperatively. A satisfaction questionnaire accompanied the postoperative questionnaire.

Results:

At 6 years follow-up, PDQ-39 scores were unchanged from preoperative scores except in the stigma domain which showed a significant improvement. There was no significant difference between the postoperatively rated expected PDQ-39 summary score and the postoperative actual PDQ-39 summary score. However, there was a significant difference between the preoperatively rated expected PDQ-39 summary score and the postoperative actual PDQ-39 summary score. Patients remained highly satisfied with the outcome of surgery (mean satisfaction score 83%). Satisfaction did not correlate with PDQ-39

summary scores, domain scores or fulfilment of expectations. The more satisfied patients (satisfaction ≥ 80%) changed their expectations so that their postoperatively rated expectations reflected a less favorable condition whereas no such change was seen in the less satisfied (satisfaction < 80%) patients.

Conclusions:

Patients remain highly satisfied with STN DBS 6 years after surgery although quality of life assessed by the PDQ-39 may return to baseline levels. Patients' expectations change over time and may influence patient satisfaction. Managing expectations before and after surgery plays an essential role in STN DBS.

Introduction

Deep brain stimulation of the subthalamic nucleus (STN DBS) is an established treatment for advanced Parkinson disease. The importance of patients' expectations in STN DBS is increasingly recognized.[1] However, there is a paucity of studies on this topic, particularly with long term follow-up. The manifestations of Parkinson disease is complex, with both motor and non-motor symptoms which affect various spheres of daily functioning.[2] In these contexts, Patient Reported Outcome Measures (PROMs), including patient satisfaction, play an important role in outcome assessment, and patients' expectations of the benefits of the proposed treatment can have an important bearing on patient satisfaction.[3,4] Patients who are not satisfied with DBS may be more reluctant to engage with treatment plans and suffer adverse consequences.[5] On the other hand, greater satisfaction may empower and engage patients more, and in doing so facilitate a better outcome.[6] Understanding patients' expectations is also important from the standpoint of formulating individual treatment goals, which provides a framework for outcome assessment. However, the relationships between expectations, satisfaction and outcome are not well understood.

STN DBS has been shown to improve quality of life in patients with Parkinson disease from 6 months to 3 years postoperatively.[7-11] However, quality of life may return to preoperative levels at 5-8 years.[12, 13] In our previous study, we reported the relationship between preoperative expectations, satisfaction and outcome at 6 months follow-up after STN DBS.[14] We found, in agreement with other studies,[7,9,11,13] a significant improvement

in quality of life assessed by the PDQ-39. We also found, uniquely, that the magnitude of the expected change rated preoperatively was significantly greater than the actual change that occurred, and that satisfaction at 6 months follow-up correlated with fulfilment of expectations rather than changes in PDQ-39 scores.[14] Little is known about patients' expectations and satisfaction in the longer term, particularly when symptoms may progress due to the natural history of disease, despite stimulator adjustment. In the current study, we aimed to extend the findings of our previous study by repeating the same assessment 6 years after surgery in the same cohort of patients.

Methods

Our previous study included 19 consecutive patients with advanced Parkinson disease who underwent STN DBS at our institution.[2] Patients completed a modified PDQ-39 questionnaire which was administered preoperatively and then posted to their address 6 months postoperatively with a satisfaction questionnaire. The modified PDQ-39 contains the full PDQ-39 with an additional instruction to record the expected change for each item of the questionnaire (Appendix 1). In the preoperative questionnaire, the patient was instructed to record where they would expect to be after surgery. In the postoperative questionnaire, the patient was instructed to record where they expected themselves to be at that time point (Figure 1). Details of patient selection, informed consent and surgical procedures are reported previously.[14] In the current study, the questionnaires were posted to patients 6 ± 1 years after the date of surgery. By this time, one patient had died of an unrelated cause, one patient developed severe dementia and two patients were lost to

follow-up, resulting in a cohort of 15 patients which we report here. The preoperative and 6 month data from the previous study which we report here for comparison are derived from the 15 patients who were available for the 6 year follow-up, other than for comparisons for the expected PDQ-39 scores which are based on 12 patients due to incomplete data in 3 patients.

Data Analysis

Data from the questionnaires were coded according to the PDQ-39 manual[15] and analyzed in SPSS version 20 (SPSS Institute, Chicago, Illinois, USA). The Wilcoxon signed rank test was used for comparisons of the preoperative and postoperative PDQ-39 actual and expected scores as data were not normally distributed. Correlations were tested using the Spearman's test. P values less than 0.05 and correlation coefficients above 0.3 and below -0.3 were considered to be significant. The no change hypothesis imputation[2] was used for missing values, which accounted for 1.9% of the data.

Results

There were 9 males and 6 females. The mean age was 60.5 ± 6.4 years. The median disease duration before surgery was 10 years (range 5-15 years).

Quality of life (PDQ-39)

The preoperative, 6 month and 6 year PDQ-39 summary and domain scores are presented in Table 1. At 6 years postoperatively, there was no significant difference in the PDQ-39 summary score and most of the domain scores compared to the preoperative score. The only domain that showed a sustained significant change at 6 years was stigma, which improved. These results are in contrast to those seen at 6 months, which showed significant improvements in the PDQ-39 summary score and the mobility, ADL, stigma and bodily discomfort domains.

Expectations and satisfaction

There were no significant differences between postoperatively rated expected and postoperative actual PDQ-39 summary scores at 6 months (p=0.104) and 6 years (p=0.117). However, there was a significant difference between the preoperatively rated expected score and postoperative actual scores at both 6 months (p=0.002) and 6 years (p=0.001) (Figure 2). 15 patients completed the satisfaction questionnaire at 6 months and 6 years (Table 2). At 6 years, patients remained highly satisfied with the outcome of surgery (mean satisfaction score = 83%). Virtually all patients felt that they had made the right decision about surgery, that they would have the surgery again, and that they would recommend surgery to other patients. The mean score for adequacy of the information patients were given before surgery was 82%. The mean score for surgery meeting overall expectations was 83% at 6 years. Satisfaction with surgery correlated with fulfilment of expectations at 6 months (r^2=0.92, p <0.001) but not at 6 years (r^2=0.18, p=0.114). We grouped the patients into a more satisfied group (satisfaction score ≥ 80%; 9 patients) and

a less satisfied group (satisfaction score < 80%; 3 patients). There was no significant difference in sex distribution, disease duration and age at surgery between the two groups. The more satisfied group changed their expectations so that their postoperatively rated expectations reflected a less favorable condition (p=0.01) while no such change was seen in the less satisfied group (p=0.89) (Figure 3).

Discussion

Our observation that quality of life measured by the PDQ-39 returns to baseline levels over an extended (6 year) period is in accordance with two other long-term follow-up studies of STN DBS which evaluated quality of life with the PDQ-39 at 5 years or more follow-up, and is consistent with the progressive nature of Parkinson disease.[12, 13] In the current study the only domain that showed a sustained significant change at 6 years was an improvement in stigma. This may be an indication of the empowering nature of DBS as an intervention which continues to give patients the self-confidence to deal with everyday situations. The communication domain showed a substantial deterioration of 73% at 6 years compared to preoperative baseline, also consistent with the two other long-term studies.[12,13] The reasons for this could be multifactorial but the deterioration in speech which accompanies the natural history of the disease could be a contributory factor.[13] DBS itself can have adverse effects on speech,[16] and patients require judicious support to manage the changes associated with DBS.

The significant difference between preoperatively rated expectations of the surgical outcome and the actual outcome evaluated by the PDQ-39 at 6 years mirrors our previous findings at 6 months follow-up and indicates the disparity between preoperative expectations and postoperative outcome.[14] However, the finding that postoperatively rated expectations of outcome do not differ significantly from actual postoperative scores at both 6 months and 6 years (Figure 2) suggests that patients' expectations may change after surgery and may align more with their actual status. The process by which this occurs is not known but interactions with healthcare teams, changes to the social environment and changes in individual perceptions may contribute. In the domain of stigma, in which the most sustained long-term improvement was seen after DBS, patients expected to be worse than their actual PDQ-39 scores. In contrast, in the domain of communication which showed the most substantial deterioration, patients expected to be better than their actual PDQ-39 scores. These findings emphasize the importance of preoperative counselling and expectation management throughout the patient journey.

Satisfaction is a multidimensional concept and can be broadly divided into satisfaction with the outcome of a treatment and satisfaction with the process of a treatment.[6] Satisfaction of outcome after DBS has been assessed by semi-structured interview and questionnaires.[5,17] An open in-depth interview study showed that up to 25% of patients may perceive their outcome as negative one year postoperatively, and preoperative apathy and axial symptoms predicted dissatisfaction with STN DBS.[5] In another study, patients with perceived negative outcomes were characterized by unrealistic expectations preoperatively, no postsurgical improvement in quality of life, and significantly higher

preoperative and postoperative apathy and depression scores.[17] Our previous study showed that satisfaction at 6 months correlated with fulfilment of expectations[14]. However, at 6 years, satisfaction did not correlate with fulfilment of expectations even though patients overall remained very satisfied with the outcome of surgery. It could be hypothesized that some patients may have remained satisfied due to adjustment of expectations. However, some patients reported high levels of satisfaction despite lesser fulfilment of expectations, suggesting that higher satisfaction can be achieved even if the desired outcomes may not have been achieved. The factors that determine the relationship between expectations and satisfaction are complex and may vary with time. Further study is required to determine how these dynamic factors can be influenced to provide better outcomes for individual patients.

This study is limited by the small sample size drawn from a single center and larger studies are required to verify the findings reported here. The results are however supported by appropriate statistics, and given the highly individualized nature of DBS surgery we believe that small groups of patients, particularly in an area such as expectations, contribute valuable data in order to improve the quality of care. None of the patients in this cohort suffered from complications. This may add a further selection bias, as patients who suffer adverse events may report lower satisfaction and a greater disparity between actual and expected outcomes. Moreover, patients may also suffer from subjective complications which are not fully reported to the healthcare team, although we did not explore this as part of this study. The limitations of our questionnaires, including the use of a non-validated, modified version of the PDQ-39 and satisfaction questionnaire

have been discussed previously.[14] Despite these limitations, the role of expectations after DBS has received scarce attention in comparison to other surgical specialties[18-24] and we believe that these results indicate an important role for expectations in STN DBS for Parkinson disease that merit further study.

Conclusions

Patients remain highly satisfied with STN DBS 6 years after surgery, although quality of life assessed by the PDQ-39 may return to baseline levels. Patients' expectations change over time and may influence patient satisfaction. Managing expectations before and after STN DBS therefore plays an essential role in delivering the optimum care for the individual patient with Parkinson disease.

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Figure Legends

Figure 1

Timeline of questionnaires

Figure 2

Boxplot of actual and expected PDQ-39 summary scores before surgery, 6 months after surgery and 6 years after surgery. The preoperative expected score is a preoperative rating of where the patient expected to be after surgery. The postoperative expected scores were rated at the respective postoperative times. The expected scores increase with time suggesting that expectations change with time.

Figure 3

Relationship between satisfaction groups and expectations.

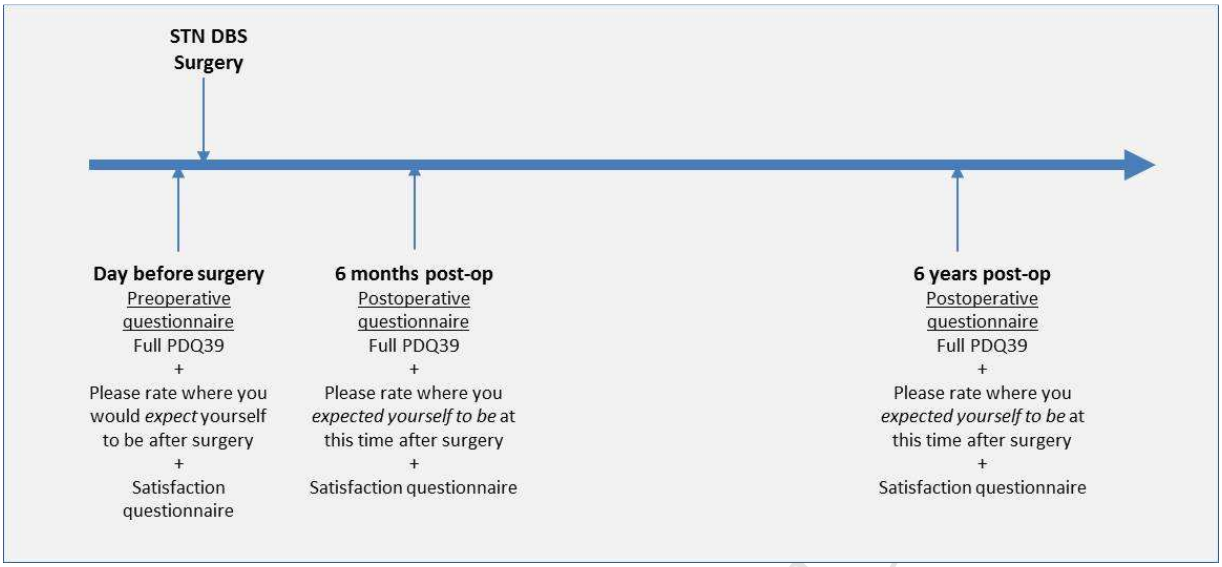
Table 1: PDQ-39 scores before and after bilateral STN DBS

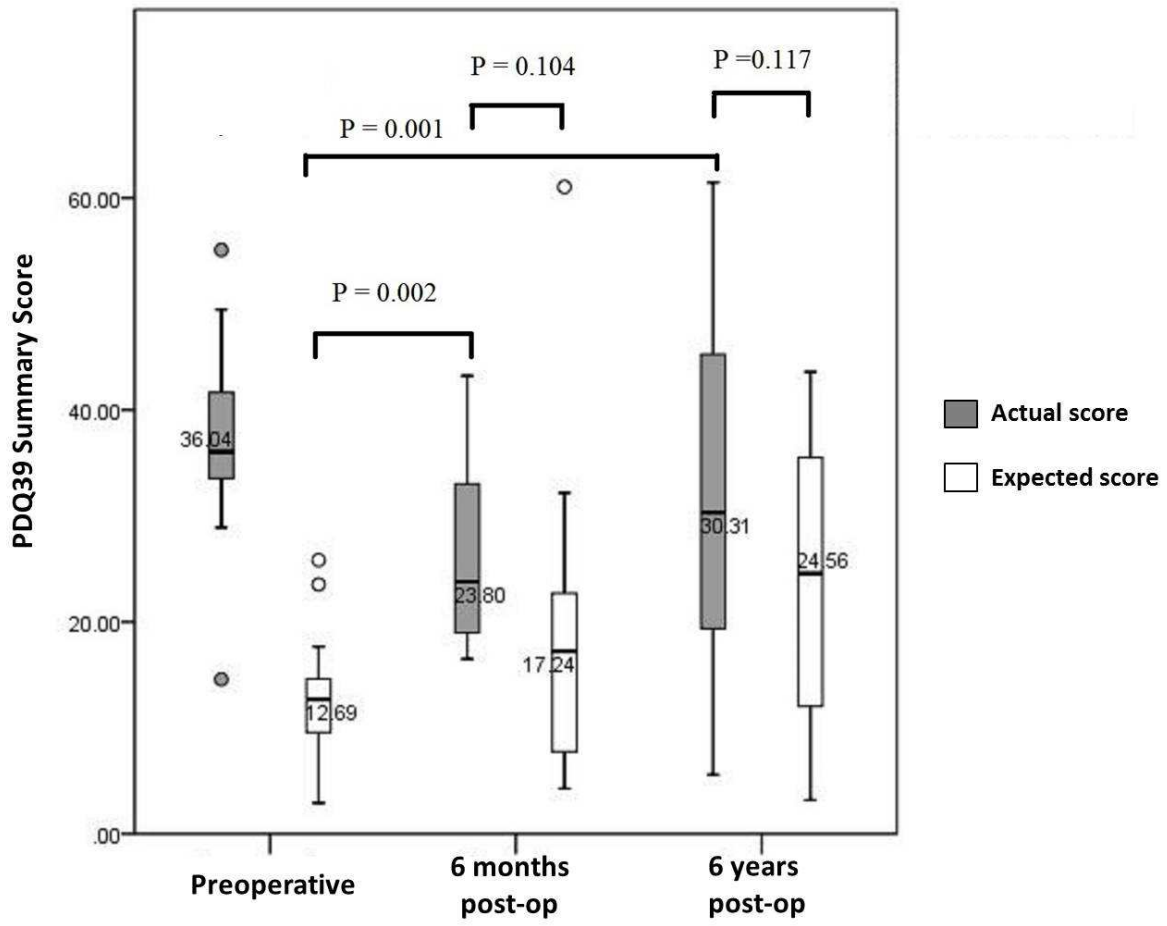
	Preoperative score (Median/IQR)	Postoperative score (Median/IQR)		P-value	
		6 months	6 years	6 months	6 years
Total score	36.0 (9.4)	23.8 (18.0)	30.3 (26.9)	0.005*	0.347
Mobility	37.5 (40.0)	25.0 (35.0)	45.0 (25.0)	0.016*	0.712
ADL	41.7(25.0)	25.0 (25.0)	41.7 (45.8)	0.022*	0.339
Emotional well-being	29.2 (25.0)	25.0 (29.2)	33.3 (29.2)	0.106	0.584
Stigma	43.8 (37.5)	16.7 (37.5)	12.5 (31.2)	0.007*	0.011*
Social support	0.0 (33.3)	0.0 (33.3)	25.0 (33.3)	0.611	0.397
Cognition	37.5 (12.5)	25.0 (31.2)	31.3 (37.5)	0.097	0.569
Communication	16.7 (33.3)	16.7 (33.3)	33.0 (33.3)	0.85	0.063
Bodily discomfort	50.0 (41.7)	33.3 (41.7)	25.0 (50.0)	0.045*	0.181

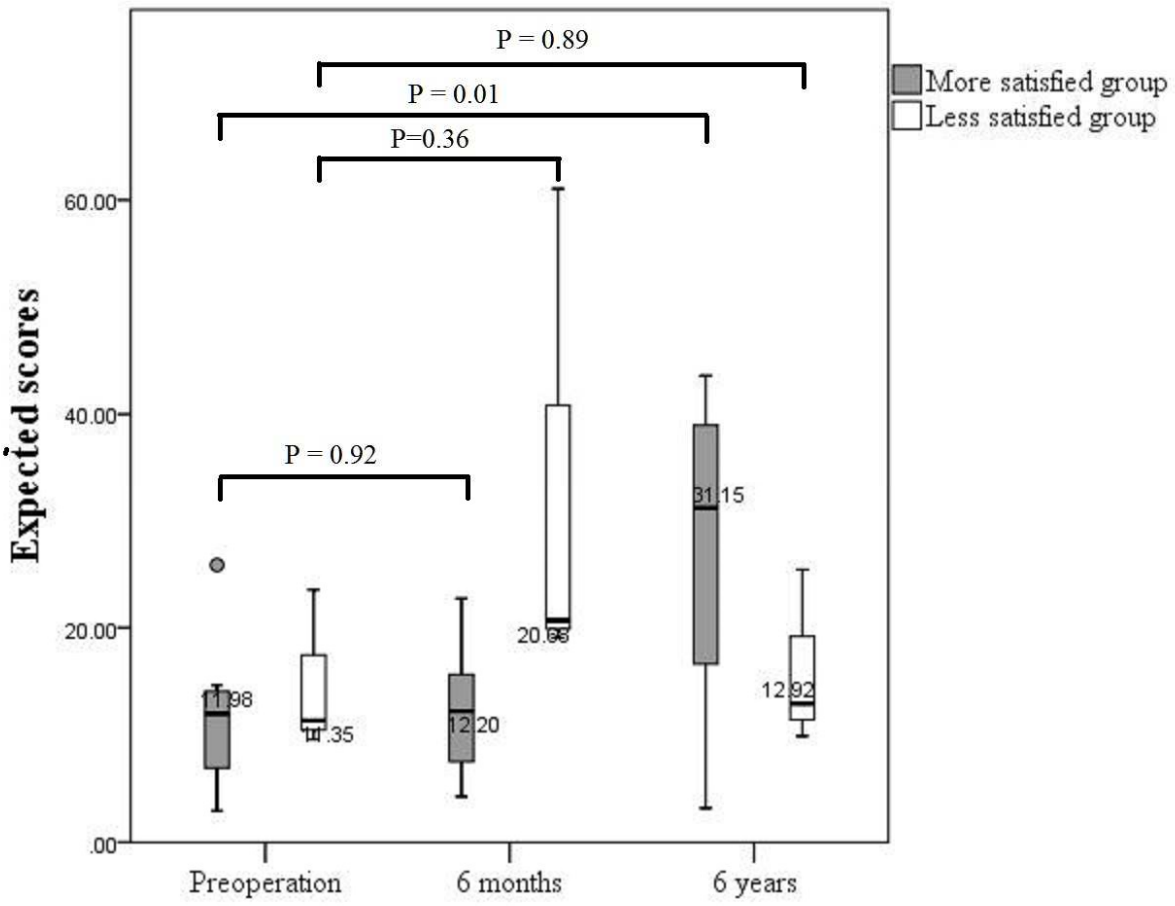
* Significant when $p<0.05$

Table 2: Responses to satisfaction survey (n=15, % for scales indicate mean scores)

	Percentage	
	6 months	6 years
How satisfied are you with the overall outcome of surgery?		
Not satisfied 0—10—20—30—40—50—60—70—80—90—100 Satisfied	80	83
Do you think you made the right decision about surgery?		
Yes	93	100
No	0	0
don't know	7	0
Would you have it done again?		
Yes	73	93
No	7	0
don't know	20	7
How well do you think the information given to you before surgery prepared you for it?		
Not prepared 0—10—20—30—40—50—60—70—80—90—100 prepared	82	82
Would you recommend it to other patients?		
Yes	87	100
No	0	0
don't know	13	0
Overall, by how much has surgery met your expectations?		
0—10—20—30—40—50—60—70—80—90—100 Did not meet expectations at all — Met all my expectations	81	83
If in the future you should become unable to decide for yourself, would you still want a battery change when indicated?		
Yes		100
No		0
don't know		0




P = 0.104
P =0.117
P = 0.001
P = 0.002
60.00
40.00
20.00
.00
PDQ39 Summary Score
36.04
12.69
23.80
17.24
30.31
24.56
Preoperative
6 months post-op
6 years post-op
Actual score
Expected score


P = 0.89
P = 0.01
P=0.36
P = 0.92
More satisfied group
Less satisfied group
Expected scores
60.00
40.00
20.00
.00
31.15
12.92
12.20
Preoperation
6 months
6 years

Highlights

- Patients remain highly satisfied with STN DBS 6 years after surgery
- Patients' expectations change over time and may influence patient satisfaction
- Managing expectations before and after surgery plays an essential role in STN DBS

Abbreviations:

ADL: Activities of daily living

DBS: Deep brain stimulation

PDQ-39: 39-item Parkinson disease questionnaire

STN: Subthalamic nucleus